INQUEST
TRUTH, JUSTICE & ACCOUNTABILITY

INQUEST Evidence Report for the Equalities and Human Rights Commission's (EHRC) Inquiry into non-natural deaths in detention of adults with mental ill health between 2010 and 2013

December 2014

POLICY • ADVICE • CAMPAIGNS

INQUEST Report for the Equalities and Human Rights Commission's (EHRC) Inquiry into non-natural deaths in detention of adults with mental ill health between 2010 and 2013 of Family Listening Day Event 7 November 2014

Evidence from the families of those who have died

1. Introduction

The family listening day organised by INQUEST took place on Friday the 7th of November at the Friends Meeting House, Euston Road, London. The event was designed to help the EHRC gather evidence from the families of adults with mental health problems who had died in detention. In total 15 families attended, and were joined by INQUEST staff and seven panel members from the Commission[1].

Based in London INQUEST is a small award winning charity that has a proven track record in delivering a free in-depth specialist casework service to bereaved families following deaths in all forms of state custody or detention or involving state agents in England and Wales. INQUEST also works on other cases that that involve multi agency failings and/or engage article 2, the right to life, of the European Convention on Human Rights and/or raise wider issues of state and corporate accountability. It monitors public interest inquests and inquiries to ensure the issues arising inform its strategic policy and legal work alongside the issues arising from our own casework. INQUEST also involves bereaved families in its policy and campaigning work for change.

2. Methodology

Using its detailed case database, INQUEST identified families whose experience would be relevant to the Inquiry and invited them to participate.

Following discussions with the EHRC it was agreed, based on INQUEST's specialist expertise in organising and co-ordinating user focussed events involving bereaved families to organise a family listening day. This model has been designed, delivered and refined by INQUEST, working with Chris Tully an independent consultant, over a number of years to be a highly regarded, reputable and reliable method of feeding the perspective of families into a wide range of work streams. It was agreed to divide the session into three groups, based on the framework for the inquiry, which related to the form of custody or detention or contact with state agents: police, psychiatric detention and prison.

These groups then had an opportunity to discuss their family bereavements within the context of a number of key themes - the mental health needs of those who died, any

---

[1] See Appendix 1

factors which exacerbated their problems, the suitability of support provided to meet their needs, difficulties encountered, the investigation process post death and any examples of good practice. For the purposes of a consistent and linear approach, the key themes were framed chronologically – before and during detention, and following the death of their relative.

Each group was facilitated by INQUEST staff and was attended by EHRC Commissioners and members of the inquiry team. Following the group sessions in the morning and afternoon there was an opportunity for plenary discussion on the key themes arising. All sessions generated an encrypted recording of the conversation and all families involved were consulted on the need for a recorded version of events and were happy to participate.

This report was written by Chris Tully, who assisted in facilitating Listening Day events for the Independent Advisory Panel on Deaths in Custody, which included report writing, research and analysis, and a similar brief with the Independent Police Complaints Commission as part of its review into working with families bereaved following contact with the police. He has also conducted monitoring and evaluation, example projects for Women In Prison evaluating its Women Prisoner Advice and Information Service (WPAIS) and prior to that, its Move Out Move On employment and training programme for women offenders. He also works as a Transformative Mediator with skills in neighbourhood disputes and conflict resolution.

Chris Tully, Independent Evaluator, Trainer and Mediator – chris.tully@bakerbrown.co.uk

3. Deaths following contact with the police

There were seven cases represented by nine family members in this group.

- **Events preceding initial contact with the police**

Each family had an opportunity to outline the events that preceded the initial contact with the police. Although every case is unique, thematic similarities were identified in the families' narratives.

In all but two cases families were aware of the severity of their relative’s mental health problem and to varying degrees involved in their relatives’ care and treatment. For some of the families their relatives had experienced many years of diagnosed mental health problems. For two there was a sudden episode resulting in police involvement, whereas the others had witnessed deterioration in their relatives’ well- being in the days and / or weeks leading up to the initial contact with the police.

A number of keys themes emerged;

3.1 Failures in provision of appropriate treatment and the use of prescribed medication (often unmonitored) deemed inappropriate or counterproductive by families.

One family described how their relative had received useful support for addictions to alcohol and prescription drugs, and with group and family support had remained “clean” for two years. After being tempted to drink again he entered a “downward spiral”. He met with his GP who prescribed anti-depressants and an offer of an appointment with a psychiatrist. That appointment did not materialise, perhaps through a lack of resources, or due to a breakdown in communication between the GP and commissioning service providers. The family were concerned that barring one brief appointment to check their relative’s weight etc. no further medical consultation took place to monitor the impact of the drugs, and how quickly the medication was increased to the maximum dose. This had a hugely detrimental impact on his health leading to his subsequent arrest as his behaviour deteriorated.

3.2 Failure to listen to families’ concerns regarding the best course of action for future treatment

Other families outlined the importance of mental health services consulting with them in a way that would have best served the needs of their relatives. In one instance a relative had been known to, and in the care of, mental health services for many years. Treatment relied upon medication and the family were aware that when their relative either stopped taking the medication, or the effects began to wear off, their relative’s health suffered quite dramatically. The family tried to negotiate the difficult balancing act of liaising with the mental health team, whilst at the same time maintaining the confidence of their relative. It was felt the family were excluded from decision-making and best care options, often on the basis of confidentiality, and that this lack of communication was in no small part a factor in his subsequent death.

Another example highlighted a good working relationship with the family GP but failings on the part of the local mental health service to follow up on concerns that had been raised by the family. Their relative's mental health problems were also well known to local services, and following a family bereavement, these problems worsened, exacerbated by the use of "legal highs" in an effort to self-medicate. Questions were raised as to whether or not a section under the mental health act was required, but as their relative was not considered aggressive or violent and subsequently described by the local police as "gracious," no action was taken. However, no follow–up monitoring ensued and his health deteriorated quickly. The family stated that *"his behaviour became very strange and there were times during the day he died when people could have intervened".*

3.3 The lack of support available when relatives' stopped taking prescribed medication

Every family referred to the impact medication had on their relatives, describing the difficulties balancing the knowledge of what might happen if their relative stopped taking medication, with the lack of alternative strategies or support available when this happened, other than the familiar route of family GP.

- **Contact with the police and detention**

Key themes to emerge from the discussion included:

3.4 Use of force and restraint

This was a key concern for all the families and highlighted the role of the police when dealing with people experiencing a crisis in their mental health. What was clear from their evidence was the inappropriate use of force and restraint on people who were variously described as "ill", "vulnerable" and "scared". In two examples the family were present at the point of detention and tried to impress upon the police that a heavy-handed approach was inconsistent with the needs of their relative.

"*I saw (their relative) restrained in the back of the van and I told the police officers exactly what had been happening, I pleaded with them to take him to a hospital because I could see he was physically in trouble and that was totally ignored, absolutely and totally ignored".*

Another case involved the use of mechanical restraints which included a belt that was applied to the relatives head, *"He was arrested on a public order offence because he was shouting and having a psychotic breakdown, we have now seen the CCTV footage of his arrest. There is no de-escalation at all, he literally goes up against the police car within 30 seconds or a minute of the police arriving and he's on the ground 30 seconds later and he's restrained which is kind of the worst thing for somebody having a psychotic breakdown. So he was restrained, handcuffs behind, two leg restraints, he's put in a van, which was 60cm, a 2ft area in a van".*

"The emergency response belt was put on back to front, with a strap over his nose, pulled tight and (they) lifted his head up".

Families were extremely concerned at the way in which situations that required a calm and sensitive intervention became the exact opposite with no attempts made to de-escalate the situation, and a rapid recourse to aggression and behaviour that was seen as inhumane and insensitive. This included handcuffing a young woman with bi-polar disorder who was relapsing having reduced her medication.

"There was a point where my sister was actually in the house, I remember she was on the living room floor, and there were these two guys, six foot and they were scaring Tasha and I just said let's go into the dining room, calmed her down, got her into the dining room sat her in the chair they still had this imposing, yeah they were quite intimidating, for me they were intimidating and you know, my sister, you know in that way just seeing these two people, you know police are supposed to make you feel safe, you know in that area, just normally, you know big, I don't know these two guys seemed like they were more, and even when they took her away it was like, because they kept saying that she was aggressive and I said no she talking loud because she's scared, she suffers from bipolar, they didn't seem to understand.

It was reiterated throughout the conversation that the quick resort to use of force, the levels of force and use of restraint was simply wrong and inappropriate for people experiencing mental health problems.

"*Why are people who are having a mental health crisis being restrained at all and actually, when they're being restrained, why are they not being treated like a medical emergency?. And I think you really need to try and get that across; why don't people learn, they need to learn".*

3.5 Training

Families suggested one of the solutions to reducing the need for restraint lies with proper training. There was a call for training geared towards working with people in mental health crisis, and to see the issue as one of medical emergency, rather than requiring discipline and force.

"When the police think it's suicide they have the right kind of training techniques and they know how to handle that well, if somebody is having a mental health crisis, for some reason the mad, bad and dangerous button gets pressed and they go the other way"

It was also felt that training needed to be extended beyond the police. For those whose relatives were taken into hospitals under section 136 (MHA), questions were raised about the ability of staff there to deal with symptoms that were perceived as being threatening or aggressive, when in fact they were displaying fear, anxiety and paranoia.

"Half of these staff, in most of these institutions are not trained because they're agency staff, and that's what we found that night, they were rubbish, I'm sorry to say, absolute rubbish".

It was acknowledged that there are serious issues regarding reliance on agency staff, and that as services are increasingly commissioned by hospitals and Trusts, so the "control" over quality of staff skills becomes harder to guarantee.

The timing of when an incident takes place also concerned families, witnessing first-hand staff shortages over bank holidays and other holiday periods. It was seen as difficult to garner information as to whereabouts, treatment and well being. One person described it as a

"kind of information void that happens, if there's a serious incident or indeed a death over a bank holiday weekend, families have been potentially told something on the Friday and then they can't speak to anybody because it's a bank holiday weekend. Talking to (other) families in the context of trying to get emergency mental health treatment, another area of concern is around holiday periods, everybody always assumes Christmas is a difficult time but actually summer is when people are extremely vulnerable in mental health services because all consultants go on holiday".

It was also pointed out by two families, who had recently attended a conference at which the police training video was shown, that the training was 14 years old, and failed to highlight new methods for de-escalating situations requiring police intervention. Families had seen a more recent training film which was not being used.

3.6 Use of section 136 (MHA) and the absence of bed spaces / safety suite provision

Some of the cases discussed in this group, (and in the psychiatric detention group), highlighted serious flaws in the way section 136 (MHA) is carried out. Key factors include a lack of bed spaces at hospitals for people detained in this way, the use of unnecessary aggression, and a failure to treat the process as a medical emergency, rather than one of public order.

One person described things that had occurred over twenty years earlier,

"And he was picked up by the police, straight jacketed, injected at the police station, I don't recall by who, if it was a nurse, a doctor or the police themselves and zombified. It was awful".

Families were concerned that things had not changed much in the intervening years, and that lessons from the past had not been learned. For one, the removal of his relative happened in the family home, a situation made worse by the absence of local bed spaces.

"My sister died in a private psychiatric ward, commissioned by the local trust so she was 50 miles away from home and she was there for 9 days, she was taken from our house on the section 136 quite abruptly by police. My sister was taken away in handcuffs".

He described his sister as being frightened and agitated and responded to attempts to calm her down with family help. However the police behaviour was "intimidating" and aggressive and made the situation worse. The flaws in this process escalated with little or no communication provided to the family, difficulties in seeing their relative, and the psychiatric hospital failing to acknowledge the family's concern regarding their relative's allergies. On being sectioned no previous medical records were sought, and this included information regarding serious allergies. The official cause of death was anaphylactic shock from an unknown allergy.

In two cases relatives' had died following the intervention of police in hospitals attempting to remove patients who were detained under section 136. Families were angry at the way hospital staff had failed to respond to their relative's mental health symptoms, and instead saw them as a matter for the police. One case in particular also demonstrated how the police can play a positive role when they approach the situation sensitively. Having been admitted on a voluntary basis their relative left the hospital and was on the local train station platform. The police were called,

"the policewoman came and sat next to him and calmed him down and they said look this is what's going to happen, you don't want to upset your mother and he came back and it was fine".

Later on that night however he had become agitated and upset and wanted to leave the hospital.

"*We had left him at 8:30 and then by 9:30, basically, they'd called the police because he wanted to leave, he'd banged on the door so they said criminal damage, they called the police, anyway eventually eleven police and three women came in, took him down to the 136 (suite?) They restrained him, beat him, pummelled him, the police told the doctors to get out, how do we know this? Somebody phoned the (local paper) and that's how we knew, otherwise we wouldn't have known anything and eventually, he was restrained by eleven policemen, I mean why?*

Her son died in hospital following the restraint.

3.7 Additional observations

As with all the groups families were concerned by the lack of empathy shown to their relatives, how "treatment" at the hands of the police could be "inhumane" and "degrading". People with mental health problems were not seen as in medical need, but as problematic, difficult and a threat. This was put down to a failure to understand mental health, and for this to manifest itself amongst police and others as a call for aggression

Families were keen to consider some strategies that might prevent such future deaths. Aside from the need to reconsider the all too quick recourse to aggression and force and the training issues outlined in section 3.5, it was felt there were key recommendations that would help. These included a greater number of bed spaces to be made available for people 136 sectioned, and that following detention in this way, people are not transferred in police vans but ambulances. All detentions involving mental health should also be attended by paramedics or those with a medical background, thus reducing the risk of fatality. And crucially when people are sectioned it *" shouldn't just be to a place of safety, it should be a place of care".*

4. Deaths in psychiatric settings

There were four cases of deaths in psychiatric settings in this group, represented by 7 family members.

- Key themes

4.1 Lack of support and services prior to entering psychiatric detention

Each family described support services as being poor, inadequate or simply non-existent. Unique insight was provided by one family member who was able to describe mental health services over a 25-year period, the time his partner had been accessing support. For one family whose relative had been receiving support for anorexia, the support offered for that had been through a local GP, a consultant and counselling services accessed through her University. However when her health began to deteriorate, and her problems escalated the family found themselves fending for themselves

"The GP just increased the dose of the anti-depressants, and he told us to put all the drugs away and make sure she didn't have any access to anything, and that was it. That was the support we got".

"But her health problems had already escalated to the point where that just wasn't adequate. And there was no community mental health support at all".

Eventually it required intervention by the police, who were called after their relative went missing for three days, and at this point she was sectioned.

This absence of support was echoed by another family who felt very let down by local provision, and described service providers as being "*defensive".* Their case also highlighted the difficulties encountered by families when mental health breakdown happened over a relatively short period of time and required a swift intervention. The family had begun to notice their relative's increasingly "strange" behaviour and his increasingly paranoid state. Initial contact with the family GP offered up anti-depressants but little further advice and support. One appointment was made with a mental health service provider in their area, and following the face to face interview their son explained what had happened; "*he said 'well the lady in there listened to me and she said I was a very sensible young man who has some problems'".* However a further expected appointment did not happen and the family felt the service was unable to provide the necessary support as it was in the midst of a top down re-organisation and "*seemed to be in confusion".*

As with the previous families experience, things came to a head when the police intervened and their relative was sectioned. In a previous phone call with social services the option of sectioning was discouraged, but an alternative was not forthcoming. Over the duration of an evening the family had called the out of hours GP services but they would not attend if there was not a risk to life, and following a further call to emergency out of hours service (who seemed initially unaware as to the best course of action), the family were given the number for Social Services who called the police. The police were commended for the way they handled the situation, and although there was a great deal of "kerfuffle" at this point, managed to keep the situation calm.

For one family the process of support was experienced over a five year period, with significant missed opportunities to make meaningful interventions. Their relative had experienced some difficulties at school (including bullying), and then experienced sexual abuse. This created a profound change in their relative's behaviour and health.

A number of issues were identified: the failure of school, social services or the local authority to intervene when the family felt it was apparent their relative was becoming increasingly unwell. This eventually led to her being placed in a CAMHS secure unit.

The family also believed a missed diagnosis of a learning disability which would have meant a different course of treatment to a mental health diagnosis, *"she was never assessed as a child, they assessed her in a secure hospital in 2012 and found out that she had an IQ of 55".* This misdiagnosis resulted in care that the family felt was inappropriate,

"They'd identified it but they were treating her for a mental health condition where the standard is you read the primary condition as a learning disability. And you don't need to use medication, it's behavioural. She had eight different diagnoses through her short life, and eight different regimes of medication".

The family also identified a lack of co-ordinated care as being a huge problem throughout their relative's time under mental health services.

"At all the CPAs and all the tribunals somebody would always be missing, and always send their apologies. And nobody ever worked like a network, it was just all mismatched and all going their own little ways, and doing their own little thing, and nobody was coming together. And when she moved around her notes were just passed, cut and pasted, nobody bothered to look at anything. And nobody actually ever talked to her, I mean, she had doctors who were supposed to be her main doctors for years, and they never had a one-to-one session with her, they had never spoken to me".

For one family member the issue of support was framed in the context of a gradual decline in service provision and care options experienced by their relative. She had been accessing support for 25 years before her death in 2010, having been diagnosed with schizophrenia some 23 years earlier. Crucially key elements of what were described as a previously good service were gradually cut: fewer beds for admission during health relapses, the care on offer from nursing staff and consultants diminished, a lack of continuity within services became apparent, and what had been a good network of support involving consultant, crisis team and social worker was eventually broken up when staff who were deemed to be doing a good job got promoted, but were not replaced by staff of the same quality. The impact of these issues was felt most keenly when a mental health crisis was reached, and what was initially a relatively "easy" process of securing a bed became much harder.

"Sometimes we were able to pre-empt it (a relapse in health) by going to what was then a very, a very supportive consultant, and the same consultant, and he would get her admission".

Latterly that changed,

"But then these options just vanished, either you were literally in full crisis, full collapse or they wouldn't even consider you for admission. And sometimes the crisis team, we had them come round a couple of times at home, and they would be offering care at home. And she would be in a situation where she'd need 24 hour surveillance, there was no way I could provide that at home. And it would be a struggle to get her admitted because of the restriction on the services that had come about through ward closures.

Changes in immediate support staff were also deemed problematic. In one case, the relative's social worker got promoted and was replaced with a person who simply didn't have the communication skills, or the empathy to work as effectively as their predecessor. This was something the family attributed to work pressures caused by staff shortages and inferior training. Having absconded from a hospital ward, his relative was eventually located by the social worker. This was the incident that resulted in the admission to the secure psychiatric unit in which his relative died.

"This was the one time the social worker did her job and actually went round with the police, got her and took her back into the ward. It was the only time they actually did something, I would say, that really helped preserve her, at least for a while".

4.2 Failure to consult families to discuss appropriate treatment and care

All the families in conversation expressed their concern at the lack of consultation that took place once their relative had been detained. Each had concerns about how they were excluded from decision making, were not consulted on best care options and were surprised at how little advice or information was sought on their relative's previous mental health history. This was relevant to both family and professional records.

"They didn't ask us anything about her, they didn't ask us about her previous mental health problems, they didn't go to her consultant who treated her before, and who (she) had absolutely idolised and thought was wonderful. He really helped her. They didn't ask them or us what worked for her, what didn't work for her".

"They were very hostile to us, they, we were the enemy outright, so when we rang up and asked questions they were pretty nasty to us a couple of times"?

An illustration of the impact on care and poor consultation had a family describing their relative as being very shy, someone who struggled around strangers, but yet was asked to attend group therapy sessions which "*she would have hated*".

Others noted similar communication difficulties and examples where care decisions were taken without their knowledge. For all the families present the full extent of these decisions, regarding diagnosis, medication and treatment were not fully apparent until after the inquests had taken place. Inevitably, discovering what had gone on "behind closed doors" caused bewilderment, shock and anger.

4.3 Lack of disclosure of information whilst in detention and confidentiality

Families were excluded from key decision making processes throughout their relatives time in psychiatric detention, and the extent to which information had been held back was a major issue. This included failure to properly consult families prior to applying for an extension to a section, limited or no input into diagnosis decisions, a failure to discuss treatment plans, negligible discussions regarding the transition process from CAMHS to an Adult Secure unit, little or no information as to a relative's well-being or general health (eating, relationships, etc.) and failures to disclose incidents of self harming and attempted suicides.

For one family no information was shared regarding their relative's attempts to abscond from the hospital in which she was being held. For the family this was extremely upsetting because it altered the dynamic of their relationship and support.

"She walked into a police station in Edinburgh in the end, and so she was put into a psychiatric unit in Edinburgh. And they wouldn't tell us when they were going to bring her home, they didn't tell her when they were going to bring her home there was just no communication at all. In the end she was there for about a week. And I think she deteriorated quite a lot in that week because she was cut off from contact with the family because she didn't have a phone charger. She had been texting, and that was the way I was communicating with her. And she had been texting me a lot, and then her

phoned died, and at that point she stopped really talking to me anyway. Whereas my mum used to go and see her every day, pretty much, and she couldn't do that because she was the other end of the country".

The same family were contacted by the hospital to inform them they were considering a further section, having made a diagnosis of a personality disorder. Again the family received this information after the event, rather than being consulted as part of the process. Their relative was not keen for information to be shared with her family but by now had become very ill, and the family believe that in her state, decisions as to her future care and treatment should have been made in conjunction with them. This decision had a profound effect on her future treatment

"The whole time they were just telling us nothing, they were asking us nothing. They diagnosed her with personality disorder without talking to us. Personality disorder is developed in your teens, but the traits that they were calling personality disorder had started when she was two, and we think she had autism. They didn't talk to my parents, they didn't find out about anything about her development history, none of that stuff was done. They assumed that because they couldn't tell us things because our relative didn't want them to tell us things that meant they couldn't ask us questions. And we got no support, my parents got nothing. After she died (her mother) got a letter saying you were entitled to some carer support or something?

4.4 Transition from CAMHS to Adult services

Concern was expressed at the failure to support the family during the process of transition from CAMHS to Adult MHS, and the lack of communication between the relevant agencies involved. The family felt that the Adolescent Unit was gearing up for a course of treatment that would have resulted in their daughter eventually returning home, whereas it appeared that their daughter was in fact to be transferred to a secure Adult Unit. This decision was taken with less than a weeks' notice. There appeared to be no transition plan in place, and the unit to which their daughter was sent had been criticised in a recent Care Quality Commission (CQC) report.

"And then she was supposed to be coming from Adolescent Services where she was wanting to come home, and the home team wanted her to go to the low secure place. Nobody worked together until the very last minute before she was coming home and she was moved, we had no transition whatsoever, into an adult service and she died about 13 or 14 weeks after she was admitted".

The inappropriateness of this option, and the difference between the two units was starkly illustrated,

She was 18, the only person that she could talk to, the youngest person was 34. She was there for three months before she died. She had no music, no personal possessions, she *never left that place, she was stuck there all the time, she didn't go on leave. And we went to the CPA after six weeks and she'd had 42 incidents of ligature tying, self-harm, and the way they dealt with it was to give her more chemical restraint. People can call it medication, it's chemical restraint".*

4.5 Quality / standards of care

The families had major concerns regarding the quality of care provided to their relatives, and for some care failings and failures in implementation of agreed policies and standards only became apparent following the investigation and inquest, or internal reviews conducted by the Trusts responsible for those hospitals involved.

Families were critical of care in general terms and described their relatives "*not being looked after", "terrified"* and in one case described bullying by both staff and other patients. Another described their relatives being dishevelled, "*looked like he'd slept rough".* Others described their concerns at whether their relative had been eating and drinking, and worried that the visible signs of distress, changes in demeanour and going from taking great care over appearance to becoming disinterested in how they looked, were not being picked up by staff. The hospital environment was described as institutional, and so lacking in empathy that relatives had become utterly withdrawn, "*unable to make eye contact with me"* . One family member described the desperation on the part of their daughter to leave,

"And she begged me, she cried and everything, and they pulled her off me and took her back, and I could hear her crying. And nobody even rang me up to tell me that she had settled. They just let me out and the nurse said to me on the way out, this person who let me out of the foyer, don't worry we will keep her alive".

4.6 Procedural failings

As well as general concerns families' identified specific issues around care that related to specific procedures that were or were not adhered to. In some cases these concerns were confirmed or revealed following internal investigation or the inquest. (Broader concerns surrounding the process of engagement with investigations and inquests are outlined later in this report, see Section 6. Investigations and inquests – families' perspectives).

4.6.1 Observations

For families there were serious doubts as to the efficiency and value of observations when not conducted properly or viewed simply as a "tick box exercise". In the worst case scenarios, failure to conduct sufficient observations, or to communicate the findings to other staff, played a part in their relatives' deaths

"Our son died 36 hours after he was admitted into the mental health hospital. He had tried to self-harm a couple of times before he finally killed himself. He was put onto 15 minute inspection (observation) it was obviously just a tick-box, it was done incredibly regularly, but there was no feedback about what my son was like, his appearance or his actions. Basically he was there, and that's all they were seeking, that he was actually there".

The observation reports from another case had been seen at the inquest, and the family thought they were "*very suspicious. Like someone had gone back and post-dated them"* The observation reports had been completed in the same handwriting throughout. Their relative had already informed them that some of the nurses didn't do the observations when they were supposed to.

The decision to take a relative off enhanced observations just prior to her death, in the context of a patient who had self- harmed and attempted suicide many times before was beyond the family. Their daughter was subsequently found unresponsive with a ligature in her room at the secure unit.

"People are making decisions who shouldn't be allowed to make decisions. She received a distressing phone call at twenty past seven, it's documented. She was highly distressed, and so they put her on enhanced observation but she appeared to settle later so they took her off enhanced observation. And that all happened within 40 minutes".

"They said she'd settled, but she was suicidal and she'd had all these major incidents that week, yet they had decided to give her bedding back, let her shut her door, and then it happened just after".

4.6.2 Monitoring and assessment

Monitoring patients, and assessing the state of their mental health was seen as ineffective by families who felt due care was not given to relatives' health when they were obviously in a crisis situation. By failing to monitor effectively, patients were left with no suitable support or care. In an extreme case, one family's relative had been transferred from the unit to the local hospital to treat a minor wound following self-harm. The whole process of transfer to hospital was badly handled; insufficient staff, failure to communicate with the A&E department as to the health needs of the relative, the involvement of the local police and then transferring a vulnerable, scared man to a "place of safety" to undergo a section 136. At the police station,

"they were waiting outside in a smoking area with just this vulnerable guy. So he should have been on two-to-one observation at that stage, and he was being sectioned, and the police and the doctors had gone off, and maybe one of the health workers who should have been on that two-to-one had been asked to run some sort of errand. And (he)

pushed himself, there is a railing on this raised area, and just pushed himself head first down onto the concrete underneath".

Their son died seven days later in hospital from his head injuries. The internal investigation into his death recognised key failings, but the family could not understand why they had not been informed of his transfer to the A&E department when it expressly states in the unit's policies that a when a transfer takes place, it must be communicated to the next of kin. This did not happen.

"They made the decision that he should go to A&E to have this minor injury treated. Obviously very little consideration had been made of his mental health state".

4.6.3 Communication and referral

Another case highlighted key failings in internal communication systems which meant a patient whose health was deteriorating rapidly was not transferred to a more secure unit. Here the care of the relative was poor

"They didn't have anything for her, no records, no care plan, and she was just sat there, she was just left there to vegetate. I've watched programmes on telly about animals, and the staff that look after them, you know all the compassion and everything they put in. And they get better treated then my daughter did. They just left her there to vegetate in a lot of the sections, the people do not care, they are just closed. It's just like in the olden days, lock them away and forget about them".

A decision was taken by a consultant to refer her to a secure psychiatric unit

So the week before she died the consultant recommended she was referred. They messed up the referral so she was never referred. That was one of the factors they said contributed to her death".

4.7 Additional observations

Families also raised concerns about the lack of proper procedures and resuscitation equipment available to deal with the emergency circumstances of their relatives death. Those present also felt that empathy and compassion were absent from the services they encountered. Individual acts of goodness were noted, people who had acted well and with sensitivity. But generally it was felt medical staff were too caught up in administrative matters, and an institutional defensiveness to be truly effective as care givers.

Particular emphasis was also placed on the impact that a lack of funding has on psychiatric care.

“It’s always an issue of funding, no money for this, no money for that, and that’s where I despair. But until the different departments work together and funding is allocated effectively, as opposed to just piling money into keeping people compliant, nothing will change”.

And perhaps the most damning verdict on the service was the decline of services as witnessed by someone whose partner had been accessing care for twenty five years. He described a steady decline of community care options, pre- crisis support, the quality and training of staff, and the role compassion played.

“What I noticed over the years was that the nurses became less and less engaging with the patients. In the early years, there were even volunteers on the ward, in other words unqualified people medically, non-nurses. But they were there volunteering to sit and talk with the patients, and offer them friendship and support, emotional support, they’ve all vanished”.

5. Deaths in prison

There were four cases relating to deaths in prison represented by eight family members in this group.

- Key themes to emerge included;

5.1 Lack of support and services prior to entering prison

Initial conversation centred on the provision of mental health services prior to entry into the prison estate. Families described what they felt to be a lack of provision, a lack of secure alternatives to prison and a haphazard approach to service provision in the community. What was also clear from those present was the wishes of families were often not met, disregarded, or the type of support that was being requested was simply not available locally.

One family described their frustration at not being able to access space in a secure mental health setting for their relative who had a long standing mental illness.

“There wasn’t any support really they were talking about a care worker coming around once a week. About 6 months before he was taken into prison, I tried to get him into a secure mental health unit through our local hospital but they simply turned round and said Care in the Community. He’d had been through (Care in the Community) 3 or 4 times before and from there he went out and committed more crimes”.

Another family described the difficulty of finding suitable accommodation for their relative. He had suffered from paranoid schizophrenia for years and had been sectioned four years before his death. Following his release he was cared for by his mother, and had once fortnightly visits from a Community Psychiatric Nurse (CPN). This was not what was needed according to his family. He also relied on medication to control his health and during a change to this medication experienced a breakdown in his well- being which resulted in him becoming violent towards his father. The family had also recognised that their relative needed to be somewhere safe and secure and tried to get him into a local unit but "*we went with him to get there and the bed had been taken. This happened on two occasions, and we got there and it was sorry the bed's gone again*".

5.2 Failure to consider relatives' history of mental health problems at sentencing

Families raised concerns about how the courts failed to recognise the impact a prison sentence may have on their relative's health. What also became clear was that by removing people from their existing support networks, and in some cases placing them in prisons that geographically prevented regular visits, their mental health problems worsened.

In one case the judge recognised the need for a mental health assessment to take place, but no such assessment was undertaken, and in another it was suggested by a psychiatrist that the relative's previous case notes would be requested and he would talk to his parents.

"When he went there, there was an independent psychiatrist went to see (the relative) in Court and he was asking if he was fit for a prison sentence. He said 'I need to get information from your family doctor and I need to speak to your parent's. Neither the doctor nor us was ever contacted, we had nothing back from him, he hadn't got in touch with us".

The family were subsequently shocked at the length of the prison sentence for the assault on the relative's father. They were trying to get through to the judge and the barrister that he was too ill to go to prison. *"He was too ill there, (we were) trying to get through to them but no one listened. I was just gobsmacked."*

There was a consensus that prison, and its harsh environment where a "macho" culture thrives, and possibly encouraged, is simply the wrong place to send vulnerable people with mental health problems.

5.3 Risk of suicide and self-harm not assessed or identified properly when transferred into prison

Families raised further concern at how mental health assessments were undertaken, from medical records not accompanying their relatives into prison, to failures on the part of other agencies to forward information that may have proven relevant in future care.

"They didn't have access to the previous records which would have shown them that he had serious mental health issues. They didn't conduct the mental health assessments correctly."

Specific problems with the Prison Escort Record (PER) and initial assessment were seen as important by families. It was pointed out that if the PER does not accompany a prisoner the crucial information contained will be missing as part of the initial assessment. It was also suggested that the PER is a more accurate indicator of an individual's physical health, rather than mental health. Families also questioned why the initial assessment is carried out by reception staff, not a mental health specialist or nurse, leading to key signs of poor mental health or vulnerability being overlooked or missed. One family suggested the initial failure to conduct a proper first assessment was down to the PER record being more about "tick boxes" then actually looking at the person and making a judgement on their health during the assessment.

Families did point out that some individual prison officers did try to their best but they, and nursing staff, were overworked and let down by systemic failings.

Another perceived failing was the inability of prison staff at reception to access the information that may accompany a prisoner via SystmOne – this is an integrated administrative tool which can be accessed by prison staff, allowing the transfer of information regarding prisoner admissions, medical care and needs, prescriptions and transfer. It is a national scheme used by all prisons. However, families felt that if it was not readily accessible at initial assessment, it didn't serve much function.

5.4 Poor medical care when in prison

Families reported problems with access to support when in prison and errors with prescriptions and monitoring of medication. There were also issues with the inability to access suitable psychiatric help and care, demonstrated most commonly as inconsistencies in seeing the same psychiatrist or nurse.

"Each person in prison has a medical team, or a medical person who looked after them like a nurse and his nurse wasn't told (about her relative's transfer) and some other doctor who'd never met him before just signed him off."

One family observed;

"The initial assessment is that (their relative) had five key indicators from the mental health assessment that he's a self-harmer and potential suicide risk. They missed all five key indicators. They didn't pick up on one of them, and assessed him as a low risk of self harm and low risk of suicide and all they had to do was look at his case history and all

the indicators would have been highlighted. He would have been put on enhanced case management and then it could have been escalated out of prison, into secure mental health care".

Others reported that correct levels of medication were not adhered to and that medication changes had, in their experience of caring for their relatives prior to prison, the potential to profoundly change behaviour and mood. One family reported that when their relative was transferred from one prison to another, the medication he required to control ADHD did not accompany him, and that when medication was eventually prescribed it was half the necessary dose. Another example highlighted how the family had tried to ensure their relative received the medication required to stop tremors, but it was not available. Finally there was an acknowledgement that the lack of co-ordination and information sharing was damaging; " *It's not consistent is it, they don't all work together, they're all doing their own separate thing, and nobody speaks to the next person".*

5.5 Mental health problems seen as an issue of discipline and control, and the inappropriate use of segregation.

All families reported similar narratives on the issue of discipline and segregation being used inappropriately following episodes of mental health crisis. Behaviour that was as a direct result of mental illness was deemed to require punishment, invariably segregation, a response that families were highly critical of.

Various situations were described that highlighted the terrible impact of segregation on their relatives. These included the detrimental effect of having no contact with the "outside world". Denying access to radio, television, books and photographs, and in one case even basic human interaction was seen as cruel, and a contributory factor in their relative's death. All families agreed that segregation, by its very nature, had worsened their relative's mental health. One family member described the impact on her relative;

"They didn't give him anything that was personal, and that hurts as well. This is why when I said that he covered himself in excrement, that is completely out of character. My (relative) had OCD like you wouldn't believe, he was forever rubbing mud off his trainer and he liked his hair just so and he was very well kept, so for him to cover himself in his own mess, in all the years I've known him, 36 years, his whole entire life he's never done that, ever".

A member of the same family summed up their feelings;

"They're supposed to be used for exceptional circumstances for as short a time as possible. So if somebody's a danger to themselves or others, just for a short time, they're supposed to put them in until they calm down, but I think somebody with mental health issues, they should try and avoid putting them in there at all or be prepared to be on

constant watch. None of this five observations an hour, I think they should have somebody on watch even if it's on a monitor".

In another case a family member had contacted the prison to inform them of her concerns regarding the health of her relative and in this instance segregation was used by the prison as a safety precaution. This was not recorded on any documentation outlining why he'd been transferred to segregation and her relative viewed the decision as being detrimental, *"they punished me instead of helping me".*

The conditions pertinent to segregation can be reproduced by placing prisoners onto a "basic" regime. Although therefore not officially segregated, all "privileges" are withdrawn, and the basic staples of stability and support are removed. One man described his relative's experience,

"He was locked up for 22 hours a day. The prison staff put a sign on his door saying that if any other prisoners spoke to him they would be put on basic and if you look at the studies that have gone on in America (people) that have been locked up for 22 hours a day, they actually cause mental health problems. What is that going to do to someone who's already got mental health problems? And they did that in a double man's cell, so there were bunk beds in there. So they give him all the tools he needed (to take his own life)".

5.6 Safer cells

The role of segregation also led families to question the use of safer cells. Families felt angry and confused as to why safer cells were not used in their relatives' cases. In one example the safer cells were opposite the cell in which their relative was placed*,*

"They left my brother who had cut himself, he had a plastic knife that he'd kept from having his evening meal and he cut his wrist and they were aware of it. They left him in that cell all night with that, a made weapon. And what it was, they were more concerned about the staff safety and wouldn't go in, rather than my brother's safety. Now they could have easily, I mean they did it before, 6 men pin him down, drag him out and put him in the safe cell, physically bodily moving him, where there are cameras".

Another explained, *"They actually had safer cells and they had one available. They just didn't use it".* Reluctance to use the safer cell option resulted in relatives being left with the "tools" to attempt to end their lives, something that in the families' opinions could have been avoided.

5.7 Administration of Assessment, Care in Custody and Teamwork (ACCT).

All the families were critical of the system for assessing custody care needs and the teamwork involved. Having entered prison with diagnosed mental health problems it was expected that all four of the families' relatives would be placed on an ACCT. The process of assessing needs, observing changes in circumstance and then following the required processes to treat and care for each individual simply failed to happen. In two of the cases the individuals were not on an ACCT at the point when the death occurred. This was despite clear signs that they were in mental health crisis, and were displaying signs that should have set *"alarm bells ringing."* In one case suicide had been attempted, but it was later revealed at the inquest that he was not deemed sufficient risk to warrant a care in custody assessment. In another case the family's relative had started to ignore their personal hygiene, and his mental health was deteriorating. This behaviour was seen as a disciplinary matter, rather than a health concern, and he was subsequently placed on segregation on a different wing where he later committed suicide. At the time of his death he was not on an ACCT.

There were also failures to cross check other records to determine the appropriateness of an ACCT, and to properly reference previous health records (as described previously with regard to SystmOne). For one family this meant there should have been an ACCT in place but *"there wasn't but there should have been and it should have been on the medical records on the SystemOne, but there was nothing. And obviously that caused concern and the prison were on the phone at the inquest saying who was on duty that day, and lucky for me I had it in writing from the psychologist saying that she told someone at (the prison) that so (lack of) communication was a big factor. SystmOne is in place so that each prison can communicate on mental health and I think it's not been used properly".*

For those that were on an ACCT there was evidence from the families that the correct processes were not being adhered to. One relative **"***was on an ACCT and less than 24 hours before he committed suicide he told them exactly what he was going to do and none of it got raised".* This is in spite of the obligation to make a note in the Wing records, or the prisoner's case notes.

One of the purposes of an ACCT is to work with all those that may have an input into the care of the individual. None of the families present had been invited to an ACCT review, and none had the chance to feed into their family member's care and treatment plan prior to death.

5.8 Communication failings between families and the prison.

It became clear during the conversation that this was a two way process and a lack of communication with their relatives proved distressing for families. Families felt that prisons did not listen to their concerns, and as a result vital information which may have saved the lives of their relatives was not acted upon.

One family member had contacted the prison to warn them of her relatives suicidal thoughts, *"We had phone calls where he said if I go back to a closed condition, meaning a Cat A, B, or C, he will commit suicide. At the same time we were coming up for his release and he had a couple of home visits and we had an independent psychologist report as well as his solicitors and we were up against a (inaudible) against his release and I then told her that he had suicidal thoughts because he went back to a Category C, he was kind of getting out of control in an open prison, (prior to his potential release he was becoming more anxious). But there was no support you know".*

Another described how the prison had informed their relative that he was not permitted to speak to members of his family. This meant that for the six months he served in prison prior to his death he had no communication with his family at any point.

"In the 6 months that he was in (prison) there was 14 occasions of threats of self harm, 7 occasions of self harm and 3 occasions of attempted suicide, and …we never heard from him once. The prison had been told that he wasn't allowed any contact with any family, letters, phone calls or anything. We'd been writing to his warden and to his solicitors and no one had explained this to us, even until the day that he had died, he was told that he wasn't allowed contact with us and there was no reason for it. For that whole 6 months we had no contact.

Families felt that the "macho" environment is such that admitting "weakness" or vulnerability is counter to prison culture and therefore the onus of responsibility lies with the prison to pass on this information. Families complained of being told that confidentiality prevented information being communicated.

Families believed telephone calls to be a "lifeline" but their use had been denied, or because they happened in public spaces mitigated against open conversations regarding health and admissions of feeling unwell, anxious or lonely. Families felt the prisons had been obstructive regarding prisoners making calls, but also receiving calls, with families reporting how difficult it was to make contact with their relatives by phone. Upsettingly for one family member her relative's transfer from one prison to another was not communicated to the family. She was unaware of where her relative was, and he had been given no opportunity to pass on this information himself. It transpired that his new phone account, activated specifically in each prison had not been set up because it was a weekend.

"I know for a fact that if my (relative) had called me that weekend I would have stopped his suicide because I had done once before, so just talking to family members (helps) and I think the issue that came up for me was because of the bank holiday weekend, and he was transferred on the weekend his calls hadn't been set up, his account. I know we think that's a perk for inmates, it's not if it's a lifeline".

5.9 Poor communication between services in prison

In all the cases discussed in this group there were concerns at the apparent failings on the part of the prisons to pass on information between departments. In these examples this centred on medical staff and prison wing staff, and the vital role that effective information sharing can have on keeping prisoners safe, and in extreme cases the preservation of life. Symptoms of poor declining mental health were missed by prison staff and not communicated, or medical staff had made an assessment that relatives should be on a medical watch or ACCT and this was not followed up. One family read from the summary findings from the inquest;

"In the days leading up to the act, there was a lack of communication from health care staff to prison staff. At the meeting no reference was made to the risk in relapse management. The report contained the key information that they claim (relative's) personal hygiene was indicative of a deterioration in his mental health. There was a failure in the system with the transfer of the information to this prison staff which resulted in critical information not being made available to all prison staff members. Consequently the problems in (his) behaviour were treated as a discipline issue rather than a medical".

Other cases saw little or no communication between prisons on transfer, and no explanation given to prisoners as to why they were being moved. This had a terrible impact on three of the cases. The sudden transfer had meant a change in regime, a change in treatment opportunities and the decisions taken meant any semblance of understanding of the individuals' care needs was lost on transfer. In each case discipline was seen to trump the medical needs of those involved.

5.10 Bullying by prisoners and prison officers.

Families reported instances of bullying by both officers, who were "caring" for vulnerable prisoners, and by other inmates. One family stated;

"other inmates have told us when my brother cut his wrists there were officers at his doorway clapping, going 'aw do you want a plaster for that son, well if you're going to do it do it right' ".

And an additional example of prisoner bullying was provided by a family who witnessed their relative with a black eye following a dispute over owed money. At this point their relative was already extremely unwell and vulnerable, and in a *"real state."*

This same family also witnessed staff bullying first hand;

"We rang (the prison) about this (additional medication), and we heard on the landing, 'is that your mother again, tell them to stop ringing the prison', this is the officer. Apparently he got reprimanded for saying that, when we got in touch with the Warden there, but yeah, it was absolutely disgusting".

One family described evidence given during the inquest following the death;

"One prison officer at the inquest was so physically unhappy that because there were other prison staff there, he couldn't say what he wanted to say, he was like 'I'd rather not say right now because people here, my bosses are here'. So he was so scared to say anything and then the coroner said do you think your job would be on the line? And he said 'yes'. So he couldn't even say what he wanted to say. So my (relative) was targeted, I felt he was targeted".

Following a conversation between the family member and her relative he admitted to her *"they can do what they want, they have my life in here, they do what they want".*

5.11 Additional observations

Families also agreed on a number of other factors that they believed had an impact on the relatives' well-being and care whilst in prison. These included a general sadness and anger at the lack of empathy displayed by staff. The actions of some individuals were described as cruel, and inhumane and there was disbelief that *"people could behave like that".*

This could be linked to another concern that families shared; the apparent lack of training amongst staff in dealing with people with mental health problems. Families felt it was important that all staff know how to recognise the signs when someone was becoming unwell or was entering a mental health crisis. Without knowing how to respond to mental illness, staff were more likely to act aggressively or in a way that made things worse.

Funding and resources for prisons was also raised with a direct correlation made between the regime, resources, staff skills and training and staff numbers. Good staff to prisoner ratios were seen as vital.

"There are some people out there who are really genuine, doing a good job, they're just bogged under, they're only human they can only do so much. So give them the man power and give them the training, and if you're not going to train them in mental health then you need to move the people with mental health problems where there is a trained professional".

6. Investigations and inquests – families' perspectives

- **Deaths following contact with the police**

Families reported terrible delays throughout the process of investigation and up to establishing a date for the inquest. Concerns around delays included;

The length of time it took to inform families of the death, in some cases not being told for hours after the time of death, and then having incorrect or vague information passed on.

Inconsistent approach to delivery of the news of the death

The amount of time families had to wait before the body of their relative was released to them.

A disparity in the time it took before families were interviewed as part of the investigation. In some cases the IPCC interviewed families prior to the death, whilst on life support in hospital, for others it was within hours of their bereavement. It could takes months however before interviews with police officers and medical staff were conducted.

"We had enormous difficulty with the IPCC, they were there within 4 hours interviewing us within 4 hours, we still believed at this point that (her son) was going to recover, he'd had a heart attack and they were coming in all guns blazing, they were very, very insensitive. They had seen the CCTV footage, which we had not, so they knew more than we did and we couldn't understand why they were literally shaking and sweating and they were thinking we didn't understand so that was a huge problem for us".

They felt it was wrong to then treat the staff involved as witnesses not suspects. One described a report in which officers had given "no comment" as their response to direct questions over the circumstances of the death.

Families were angered by what they felt to be a "defensiveness "of those under investigation, and by those carrying out the investigation. This was seen as an effort to hide the truth, to protect their own and as such discredited the whole process. This resulted in a lack of faith or trust, some felt suspicious of the investigators motives.

It was also felt the lack of information available to them immediately after the death, meant the whole process set of on the wrong foot.

Families were not routinely informed of their rights, and many felt this was down to the failure to recognise them as victims.

The information void made the investigative and inquest process a lottery – they did not receive information on support provision, heard nothing about the need for legal representation, the right to a second post mortem and were offered no on-going support during the investigation.

"We had to fight to get any information at all, we had to fight every single step of the way"

Financial matters were also of key concern. Families described the process of ascertaining eligibility for legal aid for the inquest as extremely complex and intrusive. This includes the examination of the financial records of extended family, including those who may be less involved in the investigation and inquest. This makes an assumption that everyone is of the same mind, or plays an equal part in the financial affairs of the family. There was particular anger at the state having access to the “best legal teams” but families having to pay themselves.

“It is morally incorrect that a family should have to pay a penny, under those circumstances and I think that that is something that must change and it’s got to change. It doesn’t happen so often and it’s not a great big burden on the tax payer”.

It was felt there should be more powers for the investigating bodies and recommendations should be statutory rather than a voluntary response. There was a suggestion that could enhance the effectiveness of investigatory bodies and Coroners.

“One change I would like to see is for the IPCC to have more powers, I feel quite offended frankly that the IPCC sent a very, very strongly worded letter, I don’t think it could have been more strongly worded a month after (their relative) died saying they recommended that 7 individuals were suspended and they’re still working and they’re not suspended”.

- Deaths in psychiatric settings

  There was shared concern at the long delays for internal investigations to take place, and the wait for the inquest to start. Families described the wait to find out what was going on as “*devastating”,* and caused “*uncertainty and confusion”.*

  As with the deaths in other settings, information was poor and families felt the onus was on them to chase things up, rather than to be kept in the loop. In the absence of information from the hospitals, Trusts and investigators, families were left alone and the importance of getting proper legal representation was acknowledged as crucial. “*It was only once we got our solicitor that she started digging”.* This was especially true of subsequent investigations, where it was felt the next of kin did not have their interests protected.

  “And we had no contact with the hospital whatsoever, the first time was when I wrote them a letter with our complaints, our concerns, and then I got a reply from the regional director. Not from anybody in the unit, from the Regional director, and with a comment of ‘oh we are so sorry to hear about your loss’. That was the only contact we had with the hospital. We weren’t involved in any internal enquiries whatsoever. The coroner sent us a letter saying there was going to be an inquest, but no date was fixed, so I contacted the person there, the clerk, and he said I can give you support; ‘the inquest we anticipate to last a day’, that’s all we were told.

And I got off the phone after talking to him and I said I think we need help. Nobody (from the hospital) gave us any".

Of particular concern was the lack of an independent investigatory body in the case of deaths in psychiatric settings. Internal investigations conducted by and for the Trusts involved were deemed inadequate, and failed to secure all the relevant evidence. Families were disappointed that reports missed out key information (observation records were mentioned by families in particular), had overlooked witness statements that were only re-examined after family complaints, failed to release documents to the families and, indeed, involve them in a meaningful way in the investigation.

"I mean one of the first things we asked, because we felt we didn't know what had been going on, I had so little information, so we wanted to see her records, and they refused to give us her records, they said that they were all confidential and we couldn't see them. We were at court for ages collecting them, and then she (the solicitor) got them, but it took a long time. I mean, the hospital were just obstructive, particularly the staff directly in the unit. Um, they were very, very obstructive. For example, when (she) died, we asked if there was a note, and we were told there wasn't one found. And then two weeks later we got a phone call from the secretary to say they had found a note".

Particular attention was given to the Care Quality Commission (CQC) reporting and the perceived failings in the rigour with which it carries out its duties. For some the CQC had given a "clean bill of health" to units and hospitals in which failings were identified.

Similarly families were unsure as to the efficiency of NHS England to produce reports following serious incidents in hospitals and secure units. Families felt this body was also being evasive and defensive. One family member complained about the difficulty of communications with it,

"I want to complain about the GP service that (our son) had, and I had, or rather the lack of it. I didn't like the communication, and our solicitor suggested NHS England was a possible one to complain to. But I complained in May sometime, they wanted it in before the year was up after he'd died. And they are still shilly-shallying about sending me letters and these forms, saying it's very complicated, we still need more time for us to find out about it. I think they are really dragging it out".

- **Deaths in prison**

This group re-iterated the sentiments expressed by others re: delays, absence of information and the difficulties in communicating with the investigatory body, the Prison Probation Ombudsman (PPO).

In particular concern was expressed at the amount of time between the death and notification, and the inconsistent approach for informing families. There was a particular problem with the role of the prisons. Some families were told by the police, others by prison staff and chaplain and others by a nominated Family Liaison Officer (FLO). In one case the family had still not met an official representative of the prison in which their relative died, and had instead received a pre drafted letter,

"The (prison) hasn't acknowledged us at all. I even got a letter that could only have been typed up by his secretary, basically sorry about your son's death, a paragraph, that much. There's no letter to my sister, and no letter to his partner and no letter for his children, they haven't even faced us and spoken to us personally".

The success or otherwise of the FLO seems to rely on the individual, rather than any particular procedural efficiency. Some families were very disappointed with the lack of sensitivity (in particular the release of personal effects, and in failing to acknowledge differences in internal family relationships) and how little help they were offered. "*We got a Family Liaison Officer and she couldn't give a shit, and that's putting it mildly".* For another the FLO "*was more fishing for information about where we were going to go and what we were going to do next so it looked like he was protecting the prison".* There was the suggestion that the FLOs that worked for the police did a better job than those from the prisons.

When the FLO worked well however, the support and information had a real impact. The process and what to expect in the coming days, weeks and months was explained clearly, as were the arrangements for funeral costs and even the sensitive issue of organ donation.

"*We eventually gave him a new lease of life by donating his organs, so technically he's alive to me, and the Family Liaison Officer told me about that".*

"*My Liaison Officer called me up, she chased up, she even found me a solicitor when I asked for one, and I ended up with a barrister and not a solicitor so I guess it depends on the area you in".*

Crucially the FLO also introduced her to INQUEST and from there she felt more in control of the process

Families recommended that FLOs should not work for the prison, but be employed independently.

The investigatory body (PPO) was also criticised for their failure to properly engage with families during the investigation, and for the length of time investigations took. Families were also critical about incorrect information in the ensuing reports, and the difficulty of having any questions answered,

"*I got the impression at first that oh they're fighting for us, you know they're going to be impartial. We didn't get the draft reports until April (7 months after death) and we had no contact with them up until just before they said we're going to send this through. They suggest you have somebody with you when you read it because it can be quite distressing. And when we read it, there's all the information you didn't know before. Then it said if you'd got any questions, so I write off a letter of questions, loads of them and I got a piddly little reply. Half of them hadn't been answered, half of them haven't even been acknowledged".*

"We had one dealing with them, when they come and took a statement and said we'll keep in touch with you and we'll be back to see you. We never heard from them for months and nobody ever did come back".

However where the PPO involved the family in the investigation process, and conferred on the report, the experience was deemed to have been excellent, and very helpful. This included considerations given to particular recommendations that could prevent future deaths. This did throw up the random nature of the service provided, and highlighted the "post code lottery" inherent in the system.

- **The inquest**

For those families that had completed their inquests there were a number of important issues raised.

The importance of being legally represented and the major role having a specialist solicitor / barrister plays in a "successful" outcome.

The dreadful anxiety caused by waiting for the inquest to start, and the absence of information of what to expect making this worse.

"*We heard from the coroner the week after (she) died, and he said it will be about a year. In the end it was two years that we waited, and I think a date was set maybe four times".*

. *"you get a date and you mentally and emotionally prepare for the date, and then you get another date, and then you get another date and each time your shoulders go boomph, boomph, and they take no cognisance of it. Don't give me a date if it's not going to happen, don't try and make me feel good, tell me you don't know at this present moment in time.*

Families in the deaths in psychiatric settings group talked about the importance of recognising their case needed to be an Article 2 inquest, and the role of a jury in that process. In two cases the need for an Article 2 inquest was explained by the families' solicitors, without whom they would not have known, and in one case it was the Coroner's clerk who informed the family. The one family who had been through the inquest spoke about the importance of having their relative's life and death listened to by people who were independent of the hospital and investigators. This felt like an opportunity to move from their relative from being a statistic, to a real person, something the internal investigation failed to acknowledge or achieve.

"They were very knowledgeable, they asked questions of all the witnesses, they asked them good questions. There was clearly at least one member of the jury who had some kind of medical background. And when they read the verdict they read the verdict to us, they didn't read the verdict to the coroner and that showed they really cared. We were able to show them a picture of Sarah and things as well. The lawyer managed to argue that was essential to the case as well, so they really got to see who Sarah was. They got to see the real person

In this same case however the dealings with the Coroner's office proved far from satisfactory. The family felt key evidence had been left out of the Coroner's Report and after repeated attempts to communicate with the Coroner nothing had progressed. "*The coroner did also say after I wrote to my MP, that they would speak to us after the inquest to talk about how they could improve the experience for others".* The family have heard nothing from the Coroner's Office since.

Role of INQUEST

Families did describe one crucial source of advice, support and legal expertise that filled the void of "misinformation", and that is INQUEST. It is clear that when families find out about INQUEST, either through their own research, word of mouth or from an investigatory body, it makes a huge difference in the level of family engagement with the process. It re-balances the power relationship for families, enabling them to find a voice in a system that should ultimately be serving their needs and interests.

"INQUEST held my hand from start to finish even the media work that I've been doing is all through INQUEST and without them we wouldn't have got the decision from the inquest that we did".

“INQUEST were the people for me, (they helped us get) in touch with the appropriate *solicitors for this sort of case and any other connection that we needed and I’d have regular chats with(the caseworker) and from having those informal chats things would come out that she would spot that needed to be sorted so I did find that a really good crutch”.*

“it was about 6 o’clock in the morning and she just rang INQUEST and left a message on their answer phone and they called at 9 o’clock in the morning, so they were with us within hours of (his) death and that got us help”.

“I got a call from INQUEST and I said ‘actually I’m a little bit stuck I don’t know where to go’, so they talked it through with me which is really good and that’s when I found out about legal representation. I can’t really afford it, I have a very small family, there is just me and my mum, that’s it. They said okay no problem, we understand how you’re feeling, so I felt very well looked after and I just needed someone who is actually knowledgeable in that area. I didn’t even have to speak to my solicitor to try and get her to take me on, they did it all for me”.

“I contacted INQUEST myself we didn’t get any advice from the prison. It was Inquest that helped us”.

“I printed everything off the INQUEST website and just went through it”.